

# NPCR—The First 10 Years

## Progress in registry operations...

Before they can be used—or be useful—cancer incidence data must be complete, timely, and accurate. The first task facing NPCR a decade ago was that of strengthening the availability and quality of population-based data by establishing and enhancing statewide cancer registries. Exemplary progress has since been made. NPCR now strives to maintain this momentum, recognizing that data quality improvement is an ongoing quest. Following are a few of the many examples of how program participants and partners have built, and continue to strengthen, data quality through advances in registry operations.

### At the State Level

**NPCR has enabled improvements** In the days before NPCR the Massachusetts Cancer Registry was processing 35,000 cases a year with four employees, outdated computers, an archaic database system, and little communication with other registries. NPCR support has enabled the registry to hire 18 additional staff members; to develop a relational database system that can retain multiple case reports, consolidate cases,

and provide management reports; to expand data collection to outpatient facilities; to conduct death clearance processing; and to expand its epidemiology capacity. The registry has earned gold certification from the North American Association of Central Cancer Registries (NAACCR) for three years running, is reporting incidence and mortality rates by race/ethnicity, and is producing special trend reports covering different age, sex, and disease-specific groups.

### Improvements are being objectively measured

NPCR has partnered closely with the North American Association of Central Cancer Registries, encouraging the incorporation of NAACCR consensus data standards among all NPCR-supported registries. In 1997 the association began offering annual, objective evaluations of registries' ability to produce complete, accurate, and timely data. Since then the number of NPCR registries that have achieved NAACCR certification has grown from 9 to 32.

**Operational enhancements have been many and varied** NPCR has helped the Illinois State Cancer Registry to implement case finding at all reporting facilities; perform random reabstracting studies;

automate screening of all data submissions; produce quarterly, facility-specific data quality reports; conduct advanced audits comparing the three staging schemes collected by the registry; and assess unresolved duplicate reports, computer matching processes, and cancer treatment variables.

In Michigan, the cancer registry credits NPCR support for sharply improving its communications with hospitals and laboratories and for enhancing the timeliness and effectiveness of the registry's death clearance work. Both state registries report that these and other operational enhancements have generated increasing demand for and reliance on their data.

### At the National Level

**NPCR-funded research is addressing issues of concern across state registries** As the federal agency charged with administering NPCR, CDC is supporting research that has the potential to help many central cancer registries enhance their operations. For example, a recent study conducted at the New York State Cancer Registry will provide new information about the feasibility of using existing governmental sources to obtain

follow-up data required for cancer survival analysis. Such analyses are currently unavailable in many states where resource limitations preclude timely follow-up of cancer cases.

Another NPCR study will generate recommendations for improving the completeness and quality of data relating to malignant melanoma. This project, currently in the planning stages, follows prior research that documented under-reporting of melanoma cases to central cancer registries. In another new project, data from about 25 state registries will be linked to records from the federal Indian Health Service. The intent is to help states avoid misclassifying American Indians as non-Indians, a documented problem with profound implications for surveillance and program planning among Native American populations.

Enhancing the timeliness and uniformity of colorectal cancer data is the objective of a 3-year study involving selected NPCR registries, pathology laboratories, and reporting protocols developed by the College of American Pathologists. This project aims to encourage greater standardization and use of electronic media in reporting data to cancer registries.

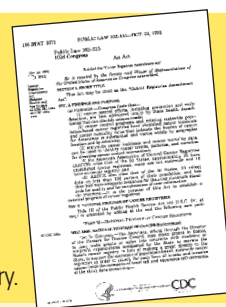
## Program origins

The origins of the National Program of Cancer Registries (NPCR) trace back to 1991, when widespread concern over the rising toll of breast cancer led many to begin asking seemingly basic questions about this and other cancers: Just how common is it? Is the incidence rate really increasing? Are certain groups or localities at greater risk?

Too often these questions could not be answered—especially in states where central, population-based cancer registries, if they existed at all, lacked the personnel, training, systems, and authority to collect complete, timely, and accurate cancer data. This was the situation in Vermont, where a grassroots campaign initiated by breast cancer survivors sought support for a national cancer registry. Cancer control advocates and national health organizations added their voices, and in 1992, led by the Vermont congressional delegation, Congress responded.

### The program today

Ten years after the passage of Public Law 102-515, NPCR supports central, population-based cancer registries in 45 states, the District of Columbia, and 3 U.S. territories (Puerto Rico, the Republic of Palau, and the Virgin Islands). Collectively, NPCR registries gather data on cancer cases occurring among 96% of the nation's population. The NPCR complements the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) program; together, these programs collect cancer data for the entire U.S. population.



1992  
Congress passes Public Law 102-515—the Cancer Registries Amendment Act—authorizing CDC to establish and administer the National Program of Cancer Registries (NPCR).

1993  
The Division of Cancer Prevention and Control gears up to implement NPCR through a cooperative agreement process.

*“A network of cancer registries can be our most potent new weapon against the disease.”*

—John H. Healey, M.D., FACS, *The Cancer Weapon America Needs Most*, Reader's Digest, 1992

*“The reason for collecting, analyzing, and disseminating information on a disease is to control that disease. Collection and analysis should not be allowed to consume resources if action does not follow.”*

—W. H. Foege, R. C. Hogan, and L. H. Newton, *Surveillance Projects for Selected Diseases*, International Journal of Epidemiology, 1976

*“The North Dakota Cancer Registry... has become a trusted public health resource in the state.”*

—Terry Dwelle, M.D., State Health Officer, North Dakota Department of Health, 2002

## **Progress in the use of registry data...**

Improvements in registry operations are a means to an end. Cancer registries exist not just to collect data, but also to make data available for use in reducing the toll exacted by cancer. Over the last 10 years, there has been exemplary growth in the quantity and variety of ways in which cancer registry data are used. This progress reflects not only improvements in registry operations and consequent enhancements in data quality, but also the work of NPCR participants in promoting and facilitating data usage. NPCR first made greater use of data possible at local and statewide levels, as individual central cancer registries were created or enhanced. More recently, as a majority of state registries have begun to generate high-quality data, new and promising applications of these data at the national and international levels have become possible. Following are a few of the many examples of progress in the use of cancer registry data.

## **At the Local Level**

### **Registry data are stimulating cancer awareness and guiding public health interventions**

Registry data are being used in analyses of observed versus expected cancer incidence in local areas where environmental factors or suspected cancer clusters have raised concerns. The Colorado Central Cancer Registry (CCCCR), for example, is analyzing observed versus expected cancer incidence in an area of north-central Denver where the U.S. Environmental Protection Agency has found elevated levels of arsenic and lead in the soil. Preparations are under way to provide targeted screening services and public education pending the outcome of these analyses.

Another Denver-area location, the Rocky Flats Environmental Technology Site (formerly a nuclear weapons plant), is the object of an epidemiologic investigation involving registry data. A roster of more than 20,000 current and former Rocky Flats employees is being matched against CCCR files to evaluate cancer risks from radiation and chemical exposures at the plant.

Data from the Nevada Central Cancer Registry have been used in an evaluation related to a suspected cancer cluster in Churchill County, Nevada. By using statewide registry data to compare local cases of acute lymphocytic leukemia to those expected, State Epidemiologist Dr. Randall Todd was able to conclude that expected incidence had been exceeded and that further investigation was warranted.

In New York, the release of zip code-level maps of lung, colorectal, breast, and prostate cancer incidence has stimulated public interest and boosted inquiries to the state health department. The geographic information systems (GIS) technology used to generate these maps has also been employed by the New Jersey State Cancer Registry, which pinpointed two areas in the state with unusually high proportions of late-stage breast cancer. To increase screenings in these areas, where residents tend to be black, Hispanic, or foreign-born, the state has disseminated culturally sensitive information about screening availability in several languages, and provided cultural sensitivity training to workers at area mammography centers.

*“Together, we have extended the reach of surveillance information beyond expectations. I have been in the cancer data arena for several decades, and the progress I've witnessed in the last 10 years is remarkable.”*

—Brenda K. Edwards, Ph.D., Associate Director, Surveillance Research Program  
Division of Cancer Control and Population Sciences, National Cancer Institute, 2002

## **A decade of progress — a brief chronology**

1994  
DHHS Secretary Donna Shalala announces NPCR funding for 37 states to develop or enhance statewide, population-based, central cancer registries.

1995  
CDC funds an additional five states and the District of Columbia through NPCR. The National Coordinating Council for Cancer Surveillance is organized.

1997  
The North American Association of Central Cancer Registries (NAACCR) institutes a process for certifying registries that meet the highest standards of data completeness, timeliness, and quality. CDC funds two additional states and three U.S. territories.

1998  
CDC funds an additional state. Nine NPCR-supported registries achieve NAACCR certification for their 1995 data.

*“A state’s cancer registry program serves as the foundation for its comprehensive cancer control efforts.”*

—Nancy C. Lee, M.D., Director, Division of Cancer Prevention and Control, Centers for Disease Control and Prevention, 2002

### **At the State Level**

**Registry data are being used to study cancer etiology, incidence, and care among statewide population groups, as well as to plan and evaluate cancer prevention, control, and treatment efforts**

The California Cancer Registry conducted a multiyear study of cancer incidence among members of the United Farmworkers of America, a largely Hispanic labor union. Among other findings, the study showed elevated risk for leukemia and for stomach, cervical, and uterine cancers within this group. This has led to plans for research into pesticide exposure and other potential causes of increased cancer risk among California farmworkers.

In addition to occupational groups, various demographic groups have become the focus of special research and interventions made possible by statewide cancer data. For example, data from the Oregon State Cancer Registry are being used in a special study of cancer among the disabled population covered by Medicaid. This project is designed to document the degree to which inadequate cancer control services among people with disabilities result in

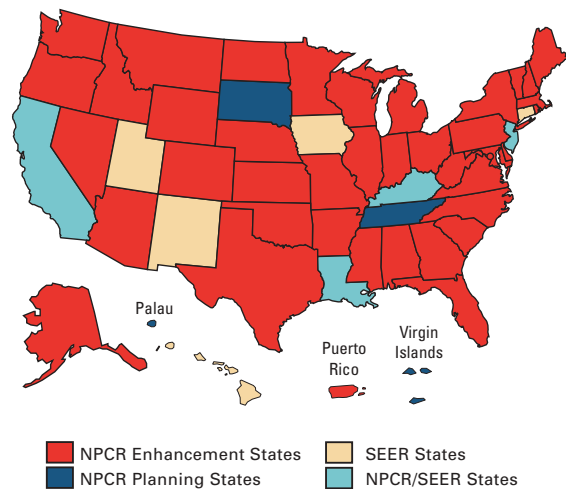
higher risk for preventable cancers and for diagnosis at later stages.

The central cancer registry in Michigan has helped to identify and recruit study subjects for research into etiologic, endocrine, genetic, and epidemiologic factors relating to prostate cancer development, behavior, and prognosis in African American men.

In North Carolina, registry data were used to identify subjects for multiyear, population-based, case-control studies conducted at the University of North Carolina Lineberger Comprehensive Cancer Center. These investigations used in-depth interviews and biologic samples to examine environmental, behavioral, and genetic risk factors influencing breast cancer development among North Carolina women.

In another project, Washington State Cancer Registry data have been used to conduct a trend analysis of inpatient versus outpatient mastectomies for breast cancer and an analysis of adjuvant therapy for stage II and III colorectal cancers.

### **State Registries Receiving Federal Support**



*“The Cancer Registry has been very useful to the Medicaid program. It has served as the basis for important health policy research work examining the issues of disparities in cancer screening stages and provision of treatment services for various socio-economic groups giving us insights into the value of health insurance and the utilization of services by the Medicaid population.”*

—Denise Holmes, Bureau Administrator  
Bureau of Policy and Federal Affairs  
Michigan Department of Community Health, 2002

*“A national system of cancer registries can help us understand the disease better and use our resources to the best effect in prevention and treatment.”*

—Donna E. Shalala, Ph.D., Former Secretary, U.S. Department of Health and Human Services, 1994

1999  
Fifteen NPCR registries achieve NAACCR certification for their 1996 data.

2000  
CDC pilot-tests the NPCR–Cancer Surveillance System (CSS) for receiving, evaluating, and disseminating cancer registry data. Twenty-nine NPCR programs achieve NAACCR certification for their 1997 data.

2001  
NPCR registries respond to CDC’s first Call for Data for the NPCR–CSS. Thirty-two NPCR programs achieve NAACCR certification for their 1998 data.

2002  
CDC and the National Cancer Institute release their first joint publication of official federal cancer incidence statistics from each state having high-quality data. The report is produced in collaboration with NAACCR.

Dear Friends and Colleagues:

Thank you for joining us as we celebrate 10 years of progress in statewide—and national—cancer surveillance. Today, we recognize with pride the accomplishments achieved in providing complete, timely, and high-quality cancer incidence data.

Ten years ago, cancer registries were described as the “weapon America needs most” to fight cancer. If you recall, in the early 1990s breast cancer was the focus of much attention for countless women in the United States; their concerns swept through the media and the halls of Congress. However, finding answers to many questions about the occurrence of breast cancer—and other cancers, as well—at the state and regional levels remained virtually impossible for the 10 states that had no central cancer registry. And other states with registries lacked the financial support or the personnel to gather complete, timely, and accurate data to ensure that the data collected met minimum standards of quality or to use their data to improve cancer control efforts. A number of states also lacked legal support for their registry, which hindered their ability to collect important information.

Responding to the needs of the states and their citizens, Congress established the National Program of Cancer Registries (NPCR) with passage of the Cancer Registries Amendment Act in 1992. As former Secretary Donna Shalala acknowledged in 1994 when the first NPCR registries were funded, “We know that the burden of cancer for Americans varies widely by geographic location and by ethnicity. A national system of cancer registries can help us understand the disease better and use our resources to the best effect in prevention and treatment.” Information derived through cancer monitoring is critical for directing effective cancer prevention and control programs focused on preventing risk behaviors for cancer, such as tobacco use. Such information is also essential in identifying when and where cancer screening efforts should be enhanced and monitoring cancer treatment and other survivorship issues for those diagnosed with the disease.

Data collected by statewide, population-based cancer registries enable public health professionals, researchers, the public, clinicians, and policy makers to better understand and address the cancer burden. The NPCR has been a pivotal step in the evolution of cancer surveillance and has provided a unique opportunity to strengthen cancer reporting in the United States. Through the NPCR, new registries have been established, many have undergone improvements and enhancements, and definite progress in the quality of data has occurred.

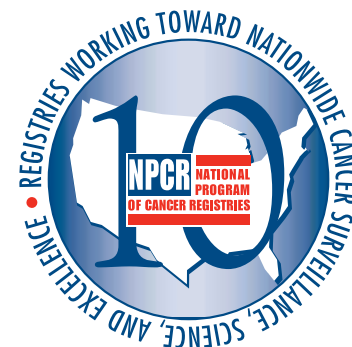
We are proud of the Program’s current progress, as exemplified in the advancements made in certifications by the North American Association of Central Cancer Registries (NAACCR), as well as in the many ways states are using their data in cancer control activities. In June of this year, in fact, we noted that 32 of the 49 NPCR-supported programs achieved certification for their 1999 data by the NAACCR—when only 9 had been certified in 1998 for their 1995 data. The *U.S. Cancer Statistics: 1999 Incidence* report, jointly prepared with the National Cancer Institute and produced in collaboration with NAACCR, signifies yet another Program milestone.

While many successes and advances have been made in the decade following the passage of Public Law 102-515, challenges still exist. A number of registries continue to address data completeness and quality concerns. Fiscal limitations result in understaffing, as well as in equipment that may not be state-of-the-art. More work is needed on specific data items, such as treatment and racial and ethnic classifications. And work continues on electronic data standardization.

To progress towards nationwide cancer surveillance, cancer registries and partners in cancer surveillance must continue to work together—dedicated to building on the accomplishments of the last decade. During the next 10 years, our goal is that ALL states will have complete, high-quality data—still the “weapon America needs most” to fight cancer.

Nancy C. Lee, M.D.  
Director  
Division of Cancer Prevention  
and Control  
National Center for Chronic Disease  
Prevention and Health Promotion

Phyllis A. Wingo, Ph.D., M.S.  
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Division of Cancer Prevention  
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National Center for Chronic Disease  
Prevention and Health Promotion



### **NPCR-Supported Programs**

Alabama Statewide Cancer Registry  
Alaska Cancer Registry  
Arizona Cancer Registry  
Arkansas Central Cancer Registry  
California Cancer Registry  
Colorado Central Cancer Registry  
Delaware Cancer Registry  
District of Columbia Cancer Registry  
Florida Cancer Data System  
Georgia Comprehensive Cancer Registry  
Cancer Data Registry of Idaho  
Illinois State Cancer Registry  
Indiana State Cancer Registry  
Kansas Cancer Registry  
Kentucky Cancer Registry  
Louisiana Tumor Registry  
Maine Cancer Registry  
Maryland Cancer Registry  
Massachusetts Cancer Registry  
Michigan Cancer Surveillance Program  
Minnesota Cancer Surveillance System  
Mississippi Central Cancer Registry  
Missouri Cancer Registry  
Montana Central Tumor Registry  
Nebraska Cancer Registry  
Nevada Statewide Cancer Registry  
New Hampshire State Cancer Registry  
New Jersey State Cancer Registry  
New York State Cancer Registry  
North Carolina Central Cancer Registry  
North Dakota Cancer Registry  
Ohio Cancer Incidence Surveillance System  
Oklahoma Central Cancer Registry  
Oregon State Cancer Registry  
Palau Registry  
Pennsylvania Cancer Registry  
Central Registry of Puerto Rico  
Rhode Island Cancer Registry  
South Carolina Central Cancer Registry  
South Dakota Cancer Registry  
Tennessee Cancer Registry  
Texas Cancer Registry  
Vermont Cancer Registry  
Virgin Islands Central Cancer Registry  
Virginia Cancer Registry  
Washington State Cancer Registry  
West Virginia Cancer Registry  
Wisconsin Cancer Reporting System  
Wyoming Cancer Surveillance Program

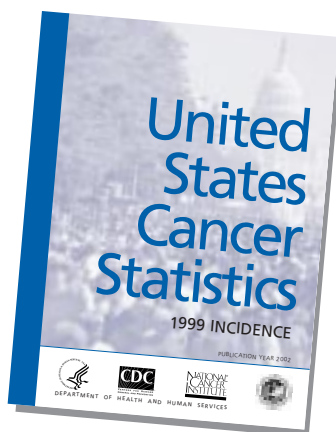
# Registries working toward nationwide cancer surveillance, science, and excellence

## At the National and International Level

### Aggregation of high-quality registry data is facilitating program planning and research across larger populations

The upcoming release of the *U.S. Cancer Statistics: 1999 Incidence* report will mark the first time that the Centers for Disease Control and Prevention (CDC) and the National Cancer Institute (NCI) have jointly produced a set of official federal cancer incidence statistics from each state having high-quality data. The report, produced in collaboration with the North American Association of Central Cancer Registries, provides state-specific and regional data for cancer cases diagnosed in 1999, the most recent year for which data are available. Cancer statistics from 37 states, 6 metropolitan areas, and the District of Columbia are included in the report—geographic areas representing about 78% of the U.S. population. This report exemplifies the progress achieved in creating a national system of cancer surveillance. Data are now available at the regional and state levels for monitoring cancer, planning and evaluating cancer control programs, and conducting research.

Use of aggregated, multi-state registry data is also supporting international cancer research. Seventeen NPCR-supported registries are participating in



the CONCORD Study, an international research project whose participants also include population-based cancer registries in 6 Canadian provinces and 16 European countries. This study is focusing on breast, prostate, and colorectal cancers to measure and explain differences in cancer survival between Europe, Canada, and the United States.

CDC is supporting several ongoing NPCR "Patterns of Care" studies involving data from multiple state registries. These investigations, which focus on breast, prostate, colorectal, and ovarian cancers, have two distinct aims: 1) to evaluate the quality of treatment and stage data in NPCR registries, and 2) to describe actual treatment patterns for several specific cancers, and estimate the proportion of patients in participating states who received the recommended standard of care for these conditions.

"...I'm acutely aware of the importance of having complete, high quality and timely cancer incidence and mortality data available for research and public health planning. Since 1995, when New York's association with the National Program of Cancer Registries began, we have made great strides forward in our cancer registry operations. New York applauds the NPCR on its tenth anniversary and looks forward to many more decades of partnership in the years to come."

—Antonia C. Novello, M.D., M.P.H., Dr.P.H.  
Commissioner of Health, New York  
Former Surgeon General of the United States, 2002

"Our Cancer Incidence and End Results Committee uses the Illinois State Cancer Registry data as the gold standard for our data collection. Our goal is to reduce the cancer mortality rates by 50% in the next 15 years, and the state registry data are invaluable in helping us determine where to allocate our time and resources."

—William Hartsell, M.D.  
Chair, CIER Committee  
American Cancer Society  
Illinois Division, 2002

## CDC-NPCR Partners

CDC works with various private-sector organizations as well as with the National Cancer Institute (NCI), the Department of Veterans Affairs, the Indian Health Service, the Department of Defense, and other federal agencies in supporting cancer control efforts. In addition, CDC participates in the National Coordinating Council for Cancer

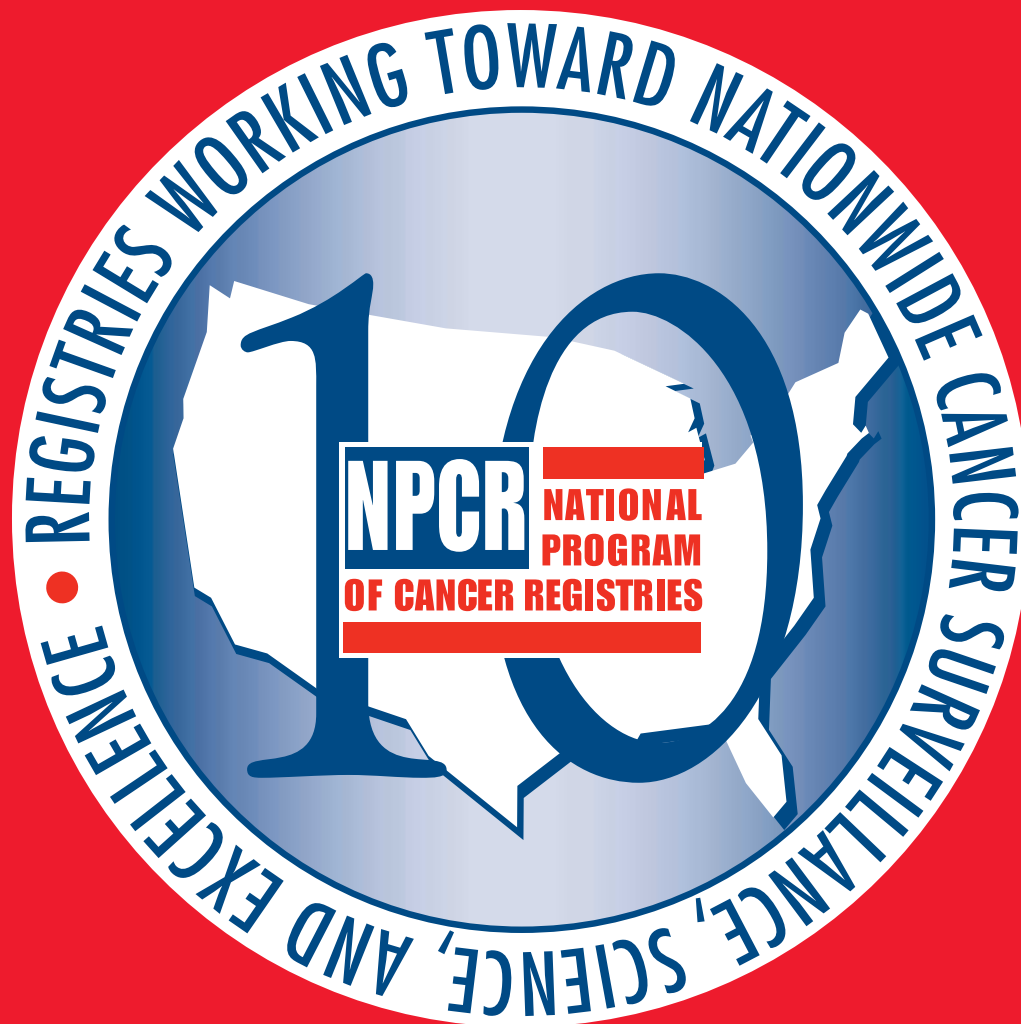
Surveillance, a consortium which also includes the American Cancer Society, NCI, the American College of Surgeons, the North American Association of Central Cancer Registries, and the National Cancer Registrars Association. The council provides a forum for these organizations to coordinate cancer surveillance activities in the United States.

## For more information, please contact:

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# *The First Ten Years*



**1992 — 2002**

**National Program of Cancer Registries**

DEPARTMENT OF HEALTH AND HUMAN SERVICES  
Centers for Disease Control and Prevention